



Children Special Health Services – Fact Sheet

Birth Defects Surveillance (LBDMN) is mandated to be statewide. Birth defects must be increased to meet this mandate from 75% to 100% coverage. CSHS clinics provide 4 levels of state-mandated services which vary depending on regional access issues. If scaled, access to community based care coordination and sub-specialty services will be increased or limited. Medical home initiative is federally mandated and should be expanded to improve national core objectives.

Objective

The purpose of CSHS is to promote comprehensive healthcare within a medical home and provide access to community based resources and subspecialty healthcare for children with special health care needs (CSHCN) through active surveillance, screening, training, care coordination, and services focused on transition to adult health services.

Performance Indicators

- % of LA hospitals included in LBDMN (N=60)
- # school personnel trained
- % CSHCN receiving care in medical home
- % CSHCN families say services easy to use
- % YSHCN receiving transition services

Narrative

Children with special health care needs (CSHCN) consume 80% of pediatric healthcare resources. Research shows these expenses are reduced when CSHCN are linked to and receive care coordination (CC) in a medical home (MH). The mission of CSHS is to assure that CSHCN in LA have access to healthcare services to minimize their disability and maximize their probability of an independent life. As part of this mission, CSHS provides a continuum of services from 0-21 years, including birth defects surveillance, screening for disabilities, linking to MHs, improving MH capacity, providing CC and access to sub-specialty care, and assisting youth with

transition to adult health care, work and independence. All of these activities support the 6 mandated Title V Block Grant national performance measures (NPMs).

The goal of LBDMN is to prevent birth defects (BDs) and BD-related disabilities in LA's children. LBDMN is an active surveillance system utilizing abstraction directly from hospital records. This is the CDC-recommended methodology for obtaining the most timely and accurate data. LBDMN objectives are providing resource information to families of children with BDs and supporting statewide BDs prevention and education activities. LBDMN collaborates with March of Dimes and Spina Bifida of Greater New Orleans in these efforts. In 2001 CSHS received an unfunded mandate to track BDs in all children ages 0–2. Expansion of LBDMN has been slow due to lack of funding. To date, LBDMN is active in 38 out of 60 birthing hospitals (approximately 75% of births). Until statewide coverage is achieved, specific rates to target preventive efforts cannot be determined. Nationally, 4 states lack a BD surveillance system and only one other system is not statewide.

In addition to newborn hearing screening (see APR), CSHS collaborates with MCH to screen high risk toddlers for hearing and speech disorders and refers to Early Steps (ES) for Early Intervention. ES, in turn, refers to CSHS for screening when needed. CSHS contracts vision specialists train pre-school and school personnel to screen school children for vision loss.

In many areas of LA, lack of transportation, subspecialists, Medicaid providers, and inability to navigate the complex system of care all present significant barriers for CSHCN. CSHS provides multi-disciplinary subspecialty clinics in underserved areas for CSHCN who meet financial and medical criteria. CC in CSHS clinics emphasizes independence from birth to adulthood, including transition to adult health care.

As Medicaid coverage has increased and access has improved in some areas, CSHS has been able to partner with private providers to increase capacity by providing assistance with CC and health coverage issues. In some cases, CSHS has been able to eliminate clinics when private sector capacity became adequate.

Better Health:

CSHS promotes better health, more affordable care, and a culture of personal responsibility by:

- Helping families identified by LBDMN to be aware of health services and community based resources
- Providing preventive education for families to make healthy lifestyle choices for positive pregnancy outcomes, in collaboration with March of Dimes and Spina Bifida of Greater New Orleans
- Providing high risk infant and toddler hearing screening and linkage to appropriate services

- Providing vision screening training to pre-school and school personnel
- Ensuring access to community based sub-specialty medical treatment
- Providing care coordination services in collaboration with family support organizations and intervention services

Safe and Thriving Children and Families:

CSHS promotes self-sufficient families and healthy and safe Louisianans by:

- Training parent liaisons to support families, link them to community resources and empower them to navigate the healthcare system
- Employing parent liaison services in all regions
- Collaborating with family support groups to improve knowledge and use of community-based services

Youth Education:

CSHS helps CSHCN achieve maximum success in school by:

- Collaborating with schools to identify and address health related concerns to optimize school attendance and participation, such as intermittent catheterization, tube feedings, administering medications, etc.
- Providing access to durable medical equipment such as hearing aids, wheelchairs, etc. to optimize school performance for children eligible for CSHS
- Providing access to needed health care as CHSCN transition to adult services

Hurricane Protection and Emergency Preparedness:

CSHS helps families to prepare for, respond to, and recover from the next emergency by:

- Training OPH nurses to care for CSHCN in special needs shelters
- Encouraging families to have their primary provider complete an AAP Emergency Information Form for Children with Special Needs that details their specific care plan
- Helping families to develop an evacuation plan that addresses their child's special health care needs

LBDMN:

LA R.S. 40:31.41–31.48 and LAC 48:V. 161, 163

Active surveillance for birth defects in birthing hospitals is the current CDC recommended methodology. Completeness is ensured by linking data with Vital Records. Birth defects surveillance can be used to determine state specific rates and patterns, which can lead to identification of risk factors. For example, Neural Tube Defects (NTDs) have been linked with folic acid deficiency. Research has shown that 50-75% of NTDs could be prevented if women take adequate amounts of folic acid prior to and during pregnancy. LBDMN supplies OPH Health Units and other sites with brochures and educational materials to help women learn about the importance of folic acid in their diets. Prevention of NTDs results in tremendous savings in suffering and medical costs.

CSHS:

R.S.40:1299.111-120. Title 48; Public Health General; Part V; subpart 27; sections 4901-5903/
LAC:48:V.4901-5903

Title V of the Social Security Act §§701-710, subchapter V chapter VII, Title 42 (53% Federal;
43% State)

Grant: MCHB Title V Grant #B04MC11257.

The MCH Title V Block Grant has 6 NPMs used to monitor progress toward a “comprehensive, family centered, community based, coordinated system of care for CSHCN”. NPMs are measured by the extensive CDC-MCHB National Survey of CSHCN. In 2001, LA was below the national average in all 6. The 2005-2006 survey showed that LA had improved to above the national average in 4 of 6 indicators (<http://mchb.hrsa.gov/cshcn05/SD/louisiana.htm>). During the 2010 MCHB Block Grant Review of past, current, and future planned activities, CSHS was told it was a “model program that should showcase its initiatives nationally”. The final report from this review is pending. In 2009, CSHS also had a stellar review with no deficiencies cited. Current initiatives focused on CC and MH are supported by extensive research

(<http://mchb.hrsa.gov/cshcn05/SD/louisiana.htm>;
[http://www.lhcqf.org/images/PDF DOCS/LHCQF Resource Tool Kit.pdf](http://www.lhcqf.org/images/PDF_DOCS/LHCQF_Resource_Tool_Kit.pdf) and
www.medicalhomeinfo.org). CSHS demonstrated significant improvement in CSHCN family satisfaction and ability of a clinic to meet MH criteria after the addition of a CSHS trained and sponsored care coordinator. The findings were presented at the LA Healthcare Quality Forum 2008 MH Summit. A paper has been submitted for publication of these results.